Arroyo, Judith 2020

Dr. Judith Arroyo Oral History

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Dr. Judith Arroyo

Behind the Mask

December 7, 2020

Barr: Good afternoon. Today is December 7th, 2020, and I have the pleasure of speaking to Dr. Judith Arroyo. Dr. Arroyo is Coordinator of the Minority Health and Health Disparities (MHHD) programs at the National Institute of Alcohol Abuse and Alcoholism. Thank you very much for being with us and talking about some of your COVID-19 activities that you have been doing both at your institute but also across the NIH. That's very interesting.

I think, let's start with your role at the National Institute of Alcohol Abuse and Alcoholism, where you've been doing a lot of work with grants and working with the extramural community. So, first, can you elaborate on the four notices of special interests that you wrote, and sort of what they were about, how you went about doing them in such a short amount of time? What was the process like?

Arroyo: Okay. First of all, my background is minority health and health disparities research. I was trained in minority health, as a clinical psychologist. That's pretty much what I have done most of my career—a lot of engaging people in the outside community to get involved in educational and research opportunities—and [I've been] doing that actually for the past 50 years now. I have been doing that for a very long time.

RADx-UP (Rapid Acceleration of Diagnostics – Under-represented Populations) came along in response to the COVID-19 epidemic. The NIH got a really large amount of money, about a billion dollars to combat COVID-19 in the U.S. public population. Surprisingly, a half of that, one half a billion dollars wase dedicated to minority health issues. Early on in the epidemic, it was recognized that it was communities of color, ethnic and racial minorities, particularly African-Americans, Native Americans, and Latinos who were not only contracting COVID-19 more often, but having much more serious involvement and so, that they were dying more often as well. If you look at maps that address infections rates in a community, they pretty much overlapped with residential patterns of the African-American community. So it was clear that something was going on with race and residence that was associated with health disparities. RADx-UP has been conducted in two phases. The first phase was what's already happened, phase two will occur in the near future.

RADx-UP phase one had to do with putting out announcements that would engage the extramural community in conducting research and encouraging ethnic and racial minorities to participate in testing, because we knew that testing is one of the conduits to keeping populations alive. It was originally intended to be not just research on testing in those populations but also research on how to engage ethnic and racial minorities more because we know that there has been a long-standing and quite understandable hesitancy on the part of racial minorities to get involved in research with the U.S. government. There have been many episodes where they got the short end of the stick where they were, basically] found to be inferior or literally were killed; I mean the Tuskegee experiment. So, we needed deal with those, in particular, we needed to do something in the face of those mistrusts of government-sponsored research, to try to get people of color involved in doing testing.

You said, the four announcements that I wrote, I, myself, did not write them exclusively, obviously. There was a team of people, many of whom were people like myself who have been involved in racial and ethnic research across the NIH. Other people were just assigned by their Institutes. You could kind of tell that there were some people who took a more active role and others that did not. We were basically told you need to spend some of this money in fiscal year 2020 and that was just literally three months before the end of the fiscal year. You usually cannot do that in that amount of time. Drafting the original FOAs, the original announcements, was in the hands of one of the co-leads on this application in this process, which is Dr. Monica Hooper from the National Institute of Minority Health and Health Disparities. She drafted these things literally overnight.

Barr: Wow!

Arroyo: Which was really amazing because she had only recently been hired as the Assistant Director of the National Institute of Minority Health and Health Disparities. She, obviously, had a lot to do with us before; she's gotten grants, she'd been on review committees, etc. But she basically got the outline of it on paper in less than a week. One of them was overnight, and then it went to the teams. We discussed what they added, what was to be included on these, and then we downloaded the drafts onto Teams, which is what you and I had just been talking about. It is a very good platform for doing edits to a document in real time. You would basically be looking at it and then things would be changing as you are looking at. It was really fun. The outlines of it, the bare bones structure, people who had more experience in writing these than I did, put those out. The nuances of how to do this in the minority community honestly, I can say that it was those of us who knew how to do research in minority communities put into the announcements.

For example, a lot of my colleagues felt that if you do something like this, of course, ethnic and racial minorities are going to get involved; sort of along the lines of "if you build it, they will come". And we all went, "Oh, no, no, no, no, you cannot write it as if we build it, you will come." So, things like [that], it is not just creating programs that will offer testing, it is encouraging uptake. The concept of uptake was something that I am actually really proud I put it in, and people were going "Why do we need that"? You need it. Writing in things like historical mistrust of getting involved in research, and nowadays it's all over the pages of the LA Times and the New York Times and stuff like that. There is acknowledgement that ethnic and racial minorities are not very willing to get involved and that there have been problems before, so, it is mistrust. Correcting nuances of how people had written things in, it was for ethnic and racial minorities as well as other vulnerable populations.

One of my colleagues had written in something about migrant populations, and I went, “Do you mean immigrant?” They go, “What's the difference?” So, we know that there is a tremendous difference between migrants, which are like migrant workers (my family were migrant workers when we first came to the United States) versus immigrants, who are people who have lived in this country for one or more generations. Concepts like acculturation, I mean, they didn't understand these because most of the people who were writing it were non-Hispanic White. We had a lot of African Americans; we had some Latinos, and we had some Native American experts as well. That is how the process ended up unfolding. It was very rewarding to understand and to see that my expertise in minority health was basically being listened to.

Barr: Great! What were some of the other [issues]? Did you take what you have learned from all your years of working with minority health and health disparities or did you go about consulting the populations that you work with particularly for COVID-19, or getting inspiration from other places on how to address their issues?

Arroyo: I think that the basics on how to get people involved, the basic FOA was written, period. But clearly, those people like myself who had specialty in working with minorities were bringing our experience. Stuff like immigrant versus migrant, community-based participatory research, it is essential. If you do not have the buy-in from the leaders of the community, and they literally have a role in developing the program and developing the research, you are not going to get people to participate. So, it was a marriage of what I know as a scientist and what I made it a point to make sure that I learned a lot about, testing and how to implement it, and the different kinds of testing, differences between FDA approved versus FDA authorized. I learned that, [and] the up-and-coming things, like saliva testing and stuff like that, in order to come up with different ideas. So, it was applying what we have learned about minority health and health disparities research over the years into a specific area.

I said that there was a phase one and a phase two. Phase two should be coming up again fairly soon, and it's going to be a similar process, to get ethnic and racial minorities engaged in the process of accepting vaccination with the context of expanding testing. As we know, in the U.S. population, only 50 to 60 percent of the general U.S. population says that they're going to be willing to get a vaccine. They are afraid that if it was too rushed, they are afraid that there may be some problems with it. Again, we are likely to have pretty much similar or even greater hesitancy, perhaps not politically motivated, but again, motivated by the experience in the past, in getting racial and ethnic minorities to be willing to get vaccinated. Okay, so now, a lot of what I am doing is a lot of webinars and a lot of listening to talks on the basics of vaccination, so that I understand better what are the questions that people might pose and the understandable hesitation under represented people, may have in order to proceed with providing useful information.

Barr: Yes. What do you think some common questions will be when it comes to the vaccinations?

Arroyo: I think that the vaccinations questions are going to be like you have seen it on the news already. Some people are going to say: Are we guinea pigs again? Remember that Tuskegee was a situation where they asked African-American men who had syphilis to be engaged in research. They said that they were basically being studied for “bad blood” and what they did is that they didn't provide treatment for them even though they were in effect being allowed to die from syphilis. All right, so, there are some populations that are very concerned that there is actually not going to be an active ingredient, that in effect there is going to be a use of ethnic and racial minorities to continue research on COVID-19, so we need to recognize that those are some of the obstacles we are up against, and to disavow people of that. Things like having President Obama being willing to have himself and his family vaccinated on film will go a long way, but there are issues.

Barr: What are some other ways that you think you can contribute your expertise to both engagement and also with the vaccine situation?

Arroyo: I know that part of what we did, what I did with RADx-UP phase one, [was] I did a lot of dissemination of the facts that we had then. I have a minority health and health disparities listserv which is, you know… basically a lot of people that know me and know what I do. I keep people abreast of what is available here and things like that. It is over 800 people, and I send out a lot of information on RADx-UP, on what was going on, on what the issues were, copies of the announcements, soliciting information, soliciting input from them if they have questions and concerns to get in touch with me. So you know that was one of the things that we did. We did some webinars on it and stuff like that but, it is using your networks to try to get the information out there, and at that point, it is also talking to the individual potential investigators who were willing to take it on, willing to take on the challenge in a very short amount of time. Because, practically, getting some of the money out in the street during fiscal year 2020 was a very, very, very collapsed time frame, and so some people were working on it nonstop for six weeks, got it in, and they run the risk of not getting funded. But we were trying to make people understand that there was one thing, where one of my bosses, actually the Deputy Director of NIAAA said to one of our potential PIs: “Dr. _____ there is a chance that this may be the most important grant you have ever written in your entire life.” It is really heartwarming to see senior leadership say things like that. It is really wonderful.

Barr: You said that in addition to conducting widespread dissemination, you have also sort of advised those who are applying, and those who are reviewing grants. In what ways did you do that, and how did you go about that for the RADx-UP?

Arroyo: Okay. For RADx-UP, what you have to do [is] you have to wait for somebody to call in and say they need help. So, whenever people who had received the FOA had a request for information, I would basically be one of the first line of information to go back out again. In addition to having them speak with a program officer on the parent grant, because the RADx-Up initiatives, except for the collaborating coordinating center, they were all done as supplements to existing grants. And making these supplements to existing grants is important because it allows it to be reviewed in a very short period of time, it doesn't have to go through a regular CSR [Center for Scientific Review] review. That, a lot of investigators didn't know, had never worked with that before we talked about that.

I know that you had a question about the caps on it too. The funding caps originally were very, very low and, particularly, in some communities of color, like Native American people living on reservations, you just cannot conduct the research for a low amount of money. We championed the idea that they needed to raise the caps on the announcements, which they did, and then, working with people to say: “Okay, is this just a prevention program or is it research on the prevention program?”—making people understand it is a combination of both. You can't write the grant for them, but you can answer the questions. That there are ways to do this, you can refer them back out to the literature. There are designs that you can use in community that are not going to give you problems, like doing randomized clinical trials. Randomized controlled trials do not work very well in communities of color, but there are other quasi-experimental designs, like step wedge designs, or wait list control designs that will fly with communities of color and would do both: the desire to get testing out into these, but also the requirement that we do decent and rigorous research on it.

Barr: Yes. You did some of the review. Can you speak a little bit about what it was like to do that?

Arroyo: Boy was that a rough one! Okay. One, we had to try to engage our colleagues at the Institutes to volunteer as reviewers because each one of the supplements still had to get three reviewers, right? So, that was interesting. You try to get people who, in addition to all the other things that they do during COVID-19, are willing to set aside time to, under very, very tight time lines, do these reviews. But it was possible.

Barr: Did they have to be related to the subject, or do they have to be removed from the subject?

Arroyo: They had to not be in conflict with the applications. That means that they could not be the principal investigator’s program official. So, they couldn't review a grant they were the program officer for. But they could be, for example, as I was able to review the ones that were related to alcohol, alcohol or drugs, or mental health since I am trained as a clinician. There were others that were not, necessarily, in those areas of expertise. The reviews were a combination, and the reviewers were a combination of people who were used to working in that content area, or used to encouraging people to write in minority health and health disparities research, and people who knew something about research rigor, and they added a statistician to every grant. And sometimes, it ended up being, as they say, a spirited discussion between those of us who were interested in getting these programs, sometimes extraordinarily innovative programs, in the community and the biostatisticians that would be grumbling about stuff like, “I didn't like their power analyses”. There was one where I literally got into a very [heated] debate that we had to impose randomized controlled trials in certain communities and I was basically responding and saying “You can't do that in communities where people are dying; they're not going to accept it.” [I had an] active role and a bit of a leadership role in all of this.

I was also allowed to be on the committees that determined the initial pay plans that were sent up the chain of review. For example, I sat on certain review groups that had to do with community level interventions and I obviously could not determine the pay plan for those. But I could help determine the pay plan for some of the others and so some of us would review something and then sit on the pay plan for the others. It was really interesting.

Barr: That is really interesting. Do you think that, you know, having this kind of involvement, thinking about minority health and the structure, do you think that will be integrated to other kinds of grants in the future? Because it seems like that would be really helpful. These issues are not new, they are just kind of highlighted by COVID-19.

Arroyo: I think that COVID-19, the COVID-19 epidemic, the startling differences in morbidity and mortality coupled with the Black Lives Matter movement, has caused a potential sea change difference in how we are addressing issues of social equity of research on health disparities. Every single IC [NIH institute or center] is examining itself for how well, what is its track record on racial and social equity in its portfolio, in its own employees, and in the who gets awarded grants, and they are hoping to make some changes again after RADx. I have been on a remarkable number of trans-NIH committees and within the NIAAA as well as committees in the Research Society on Alcoholism, the National Hispanic Science Network, and the American Psychological Association, all of which are trying to address issues of equity in health research.

So, things are changing. That is, actually, a really exciting time in which to work. I spent all my life struggling to have these issues listened to. Even though I am a pretty good scientist, and a very good team player, it has always been sort of a last thing considered, “Oh yeah, we need to think about this,” or “Oh yeah, well, maybe we'll be able to work on it someday.” Now it's on the forefront of most of the Institutes. They're interested in figuring out how to expand the quality and the quantity of health disparities research because it is one of the things that is being talked about. Even occasionally this is mentioned in the Black Life Matters agenda that the health of African Americans is remarkably more at risk not just from COVID-19, but cardiovascular disease, diabetes, obesity, and a whole host of other disorders on which we don't have enough research. It is a good time to be a minority health specialist.

Barr: Yes. What are some other things, very concrete things, that you think that NIH can do to address sort of minority health and health disparities both in terms of COVID-19 and then overall?

Arroyo: Yes. I think that the NIH can find a way, legally, to do more outreach to people who are interested in doing health disparities research. For example, I came from a really top clinical program. I came from UCLA, which was one of the top three in the United States when I graduated, but they always assumed that I was going to be doing psychotherapy in Spanish. They never really provided me with the mentorship and the training to get involved in research. Lo and behold, look to see where the heck I am! Most ethnic and racial minorities do not get mentorship on how to write a grant application, how to bounce back after you get your first review and they say you need to work on this. Okay, they, generally, get their summary statements and they may feel, “Well, okay, they didn't like that,” and then they go crawl under a rock someplace and don't come back in again. This is as opposed to anybody who knows how to play this game, knows that “Oh God, I got discussed! Let me see what they had to say. Let me see if I can fix it.” So, ethnic minorities need outreach from their program officials to understand what they need to do and what is their next step to do in order to advance their research agenda. They do not know what are the opportunities for fellowships, and entry level K awards, and senior K awards, in order to support their own salaries in order to continue to engage in the research.

Writing announcements that are health disparities related is extremely important, not just announcements that are specific to health disparities in minority health, but one of the things that I have done at my IC which has actually been fun, every single announcement that comes out from my my Institute, has to have specific language and specific bullets saying: “How can you apply for this in the area of health disparities?” So, it may be kind of artificial in a way but at least it opens the doors and people can see [that] there really is an interest in how sleep disorders affect alcohol use in minorities. Oh, and by the way, we know that African-American young people have what are the most disturbed sleep patterns. Go figure. Okay, so that you know you can put in that kind of information. It is because I have a background in this literature, that I can usually think of a bullet that works for a given announcement. Health disparities issued can relate to many research areas. And so if our announcements have at least one bullet, we hope it will increase the number of applicants that come in with health disparities topics.

[You are frozen]

Barr: Can you hear me?

Arroyo: Yeah, I can hear you now.

Barr: Yeah. Okay. I know my computer does freeze sometimes. You have talked a little bit about your background, but can you speak maybe more in detail about how your background and how your skills have informed how you have approached your COVID-19 work?

Arroyo: My background has affected all of my education and my research agenda. It is only culminated in the stuff we covered. My family were very, very poor immigrants. There were times that we had to move from one place to another. I picked crops as a kid. I did not speak English until I was in the fourth grade so, I have the lived experience of being somebody from [an] under-resourced background.

Barr: Yeah.

Arroyo: And then, somehow or another, I got this amazing education. All right. So, I also have the lived experience of knowing how people like myself, given half a chance to get in, will be willing to work themselves to death to get the education given the opportunity. I was one of those affirmative action kids. A lot of people say: “Well, you are only here because you are a minority,” and I go: “No, that opened the door, but the reason I am here is because I worked my “you know what” off to get here and because my academic credentials and my research history and my testing scores and everything else are just as good or oftentimes better than my White colleagues’ [scores] were. I have a fundamental belief that by engaging in education and by giving people a chance at education and a chance to understand how to get research funded they will do the work, you know, they really will do the work because that was my lived experience.

Barr: So, you can be more empathetic.

Arroyo: Yes, because even though I do not go and talk about my life all the time, I will at times tell people: “You know, I was there.” I mean, my first research ideas were turned down time and time again and you have a whole lot of experiences like that, and whether or not you make tenure at your first place, or whether or not you needed to go to three places before you made tenure, and people go, “You had that happen to you? And look at where you are now.” They think that program officials at NIH walk on water and it's really important for them to understand that a lot of us came here through a fairly circuitous route.

Barr: Yes. It is very interesting story. So, I guess now we will shift to more personal experience during COVID-19. It looks like you are working from home, but have you been working mostly from home during the pandemic? What has that been like?

Arroyo: I have been working exclusively from home. I am high risk. I am over 65 and I have got health conditions as well. There are times that I have not been out of the house in a couple of weeks. At first, it was extremely difficult. I was really isolated, and I am a very social person so that was an issue for me.

And then, in late June, my daughter and her husband moved into my household because they had been living in Texas. She was finishing off her master's program there online, and they had lost employment as a result [of COVID-19] so, I am not alone anymore and it has made such a big difference in my mood and my ability to do things.

They have also taught me how to do things. I now use all the platforms well. My son-in-law came, he is really good at IT, so he set me up with a system where I have two screens, I got a new router, everything works fine. They have taught me how to use Instacart and all the other things that as a dinosaur I did not use very well before. So, I am doing well now. At first, it was a little rough, but I am doing well now.

Barr: That's wonderful! Is having your daughter and son-in-law with you the main highlight, I am guessing, of the pandemic for you?

Arroyo: Yes. It is. Having them with me, having them safe, being able to help them when they get back on their feet, Now they are getting employment, they are getting back on their feet, having that in my personal life and my professional life, it has been having people really value the input that I have. I was actually on the point of retiring because I am old enough to retire now and I have lived very, very carefully in terms of my spending so, I could walk away from my job right now. I wanted to travel because I had never had a chance to travel. I was always counting my pennies and stuff so I was looking forward to that and now you can't travel. So, eventually, when I can get on an airplane and go to Machu Picchu, or the Great Wall of China, or to Africa to do a safari, I will quit, but in the meantime my input has helped, it is helpful. and it's being listened to.

Barr: You think it feels really great.

Arroyo: Yeah, it does; it really does.

Barr: Have you turned to any particular past times or hobbies to help you cope?

Arroyo: I think it's really funny a lot of us have got issues, right? It is like we know that if you are not careful, you don't do any exercise, you don't do anything like that. I forced myself to do at least a little bit of exercise during the work week and I took up needle point again. I had not done needle point in 30 years.

Barr: Oh, my goodness!

Arroyo: I thought, I am legally blind in one eye, and so, I didn't think I could do it but, I actually can do it. It was the alternative to going through Netflix and Amazon Prime, and my son-in-law taught me how to use audible books so, I listen to books now and I do needle point.

Barr: That sounds sort of relaxing.

Arroyo: Yes. It is very relaxing, and it is pretty. It is kind of artsy-fartsy. I am not very artistic, but it has been interesting.

Barr: Great!

Arroyo: My daughter cooks. She cooks very well. I am really benefiting from that, so her hobby is cooking and mine is needlepoint.

Barr: That is very nice. That sounds like a good combination.

Arroyo: Yes. It is not bad, although they have their own household, they have a full apartment downstairs and I have to be invited to dinner. We don't share our meals all the time but when I am invited to dinner, I benefit well from it.

Barr: It is really wonderful. This is a fun question. Well, I guess needlepoint, but what is something that you have taken on during the pandemic that you may think that you would continue after the pandemic?

Arroyo: So, definitely, the needle point. I am enjoying that.

Barr: What have you made so far?

Arroyo: I am working on just the first. It is very time consuming. I am working on a pillow that's going to be about this big, and so, it has taken me several weeks to do about that much of it, pretty time consuming. I am thinking that instead of buying the kits, in the future I am going to get artistic and just buy the netting and draw a picture on it myself and continue to do it from there. I sew but my eyesight is not good enough for that. I kind of manage it a little bit. When my daughter actually got married out of my household they had a really, really, really small COVID-19 wedding at the beach, and when she received her wedding dress online (everything was online) it was really interesting. It needed to be altered and so I did all the alterations on it.

Barr: Quite a COVID-19 project!

Arroyo: I am going back to basics. I was able to do it and the wedding came off very nicely. Eventually, they will have a full-blown reception with all the cultural stuff. She is Hispanic, he is half black and half Native American so they will have the native blanket ceremony and the jumping the broom and the arras y lasso de boda from our Latino culture.

Barr: Congratulations.

Arroyo: Thank you.

Barr: Very wonderful. Is there anything else you would want to share as an NIH scientist, or as a person undergoing the pandemic, with people to understand what is going on?

Arroyo: I think that the pandemic has brought out the best and the worst in people, that coupled with a really spirited and divisive political situation. I think it is important for us to listen to each other more and to reach out and listen to groups that you wouldn't necessarily listen to. For people of color, they have something to bring to the table. They have something to offer and that hopefully is the beginning of our nation and our healthcare system and our research system learning how to reach out and get the learned wisdom from communities of color.

Barr: Well, that's very well said. Thank you very much for your input and I hope that you and your family continue to stay safe and all good things for you.

Arroyo: I do hope the same for you. I hope that you find a way of [having] people around you and that you are not isolated.

Barr: Thank you.